FETZER INSTITUTE

Request for Proposals

The Fetzer Institute announces the availability of funds to support research on the role of complex human factors during the dying process and at end of life.

PLEASE POST

End of Life and the Dying Process: The Role of Spirituality/Religiousness, Human Values and Relationships

Letters of intent due January 10, 2003
Applications due May 1, 2003

Goals:

1. To better understand the role of spirituality/religiousness, human values and relationships in end-of-life care and the dying process.
2. To better understand what is valued most by people at end of life, such that care during the dying process is able to better address what is important to the dying and those close to them.
3. To promote innovative, interdisciplinary research from the social sciences, humanities, and biomedical sciences addressing the complex issues of dying.
4. To guide and encourage practical models of care that appropriately incorporate people's needs and resources in order to improve the lives of those in the dying process.

Mechanism of Support:

The total amount of funding available for this research effort is $1,300,000. The funding for individual research projects is expected to range from $100,000 to $200,000 for a period of one to two years. **The maximum amount of support is $200,000 for a 2-year project.** The funding provided may be used for personnel and supplies pertinent to the research proposed. Support can also be requested for travel expenses for the purposes of collaboration. **It is the policy of the Fetzer Institute that no indirect costs will be provided. There will be no exceptions to this policy.**

Eligibility:

Proposals may be submitted by public or private nonprofit organizations such as universities, colleges, hospitals, laboratories, or research institutions. The principal investigator must have a doctoral degree with sufficient training and experience to accomplish the proposed work. Empirical research that links biological, clinical, and/or social sciences with philosophical, ethical, and religious understanding is encouraged. Preference will be given to innovative interdisciplinary collaboration.

Background:

End-of-life care in the United States is often fragmented, painful, emotionally distressing and spiritually barren. Medical technology and economics continue to drive many discussions of quality of end-of-life care and our health care system often fails to recognize the human needs and resources of dying patients.

There is increased recognition that attention to the values of dying persons and their families and loved ones, the quality of their interpersonal relationships, as well as the spiritual and religious domains of life, can positively transform people and the experience of dying. The issues around these complex variables are rarely dealt with in end-of-life research and are not priorities in health care funding, as was highlighted at a recent conference: *Integrative Workshop on End-of-Life Research,* October 22-23, 2001, sponsored by a number of NIH institutes, other federal agencies, and the Fetzer Institute. Reports from the meeting are included in a published supplement to the October 2002 *Gerontologist.* The purpose of this workshop was to define the current state of the science of end of life in older people and to identify future directions for research initiatives. The conference dealt with a large variety of issues: ethics, economics, symptom management, practical health care issues, social support, the subjective experience of dying, and the role of spirituality, religiousness and meaning. The conference findings suggest that more scientific research is needed on the role of values and spirituality/religiousness at end of life in order to assist with practical guidance for end-of-life care.

The Fetzer Institute is taking this opportunity to encourage scientific research on a number of complex issues around end-of-life care from a full perspective, addressing patients of all ages as well as caregivers. Settings for potential research include: home, hospital and nursing homes, and the scope includes different points on the trajectory and transition from life to death. From the dying person's perspective, how do their values, their spirituality/religiousness, and their social relationships, influence the dying experience? Related variables might include: sense of control, anxiety, social and cognitive engagement, decision making, symptom control, hope, and sense of peace. From the caregiver's perspective, how does personal spirituality and religiousness affect the care and compassion toward the dying person, possible unpleasant emotional reactions to death and dying, and the potential for burnout? How does compassionate love play a part in care giving? How is the meaning and process of care giving affected by the faith of the caregiver?

Since "cure" cannot be the main aim of end-of-life treatment, there is a need to develop more inclusive models that recognize the whole person in context. Dying affects each person as a whole, and thus includes the biological, the psychological, the emotional, the social, and the spiritual components of the person.

Our understanding of a good death generally includes respect for patients' wishes and values and the extent to which they are consistent with clinical, cultural, and ethical standards. Research can add to our understanding of the values of a dying person, and his or her loved ones, and the interface of these values with society's values. Explicitly stated values often differ from those we hold implicitly and this needs to be examined carefully to achieve good decision making at end of life.

Too often our health care decisions reflect economic factors. Do health care decisions truly reflect society's values, and if not, how might we change health care in ways that support core values? Identifying exactly what values society holds in order to implement them in the end-of-life setting is a challenge.

Spirituality and religiousness are receiving increasing attention as potential health research variables in different health care settings. There is a growing body of data linking religious variables to mental and physical health outcomes. However, the particular aspects of religiousness and spirituality that have been examined

vary across studies, often resulting in a lack of clarity regarding both the construct measured and the implications of each study. Spirituality and religiousness have various meanings to people, and the words have had changing meanings over time. Research to date has often been hindered by inadequate definition. Thinking of the two concepts as overlapping parts of a multidimensional construct is a good starting point. To move forward, we need to examine the multiple dimensions of this construct, think which might be most important for the outcome of interest, and investigate those dimensions in the rich interpersonal and cultural environment.

Ten years ago, religiousness was the favored public word, but over the past ten years, spirituality has developed a more positive set of connotations. There is also a cohort effect, with older people still being more comfortable with religiousness as a descriptor. Spirituality can be conceptualized as concerned with the transcendent, addressing ultimate questions about life's meaning and purpose with the assumption that there is more to life than that which we can see or fully understand. This can be linked to formal religious affiliation and specific beliefs or not. Religiousness/Spirituality has historically been thought of as a powerful component of the multiple meanings surrounding the needs, resources and perspectives of end of life for all parties involved, and may influence end-of-life care in a number of ways. Religious/Spiritual traditions provide a set of core beliefs and values that can interface with the ethical foundation of clinical decision making, which includes caregivers' interface with life-extending technologies and advanced planning decisions. There may also be negative consequences from certain dimensions and orientations of religiousness/spirituality that create barriers to the quality of the dying experience.

In 1994, the Fetzer Institute with the National Institute on Aging, brought together a working group to develop a multidimensional approach to measuring the complex construct of religiousness and spirituality, which included domains such as religious affiliation, private practice, forgiveness, belief and experience, and spiritual and religious history. Since then, a multidimensional approach to the study of spirituality/religiousness in health studies has been increasing in applicability and usefulness, and a multidimensional approach has been tested in many health care settings and in the General Social Survey. Some of the constructs within a multidimensional approach that may be particularly useful for end-of-life research include: forgiveness, religious coping, daily spiritual experience, and meaning.

The World Health Organization (WHO) has recently developed a pilot module to be added to their standard quality-of-life instrument (WHOQOL), which examines spirituality and personal belief as a component of quality of life. This module has been developed in various cultural settings in 18 countries, and has potential for use in end-of-life research to enhance the quality of life measures currently available, and to address spiritual and religious issues. It is only recently that measures of quality of life at the end of life have begun to include the spiritual dimension.

The importance of forgiveness at end of life was emphasized in a recent report by the World Health Organization (WHO) that featured the development of a module to the WHO's quality-of-life instrument for world wide assessment of people dying from HIV/AIDS. The Fetzer Institute has a particular interest in how forgiving and being forgiven at end of life affects quality of life and the quality of dying. Feeling forgiven by the divine, and subsequent release of guilt can play a role in peace at end of life. Forgiving others and feeling forgiven by them can also be very important at end of life.

Compassionate, self-giving love, a central feature in many religious traditions, is conceptualized as a love that values the other highly and is other-centered. It is a complex variable, but has begun to be examined through scientific research. The Fetzer Institute recently supported a number of research projects under a Request for Proposals: *Scientific Research on Altruistic Love and Compassionate Love.* The Fetzer Institute is particularly interested in studies looking at this variable in end-of-life settings, and an examination of this may prove quite fruitful.

Research on relationships of the dying person with health care providers, other caregivers, family, and significant others is limited, yet such relationships and interactions greatly influence the experience of dying. At end of life people look for resources for hope, for coping with symptoms, and providing personal meaning and dignity. Relationships put human dignity and the spiritual needs of patients at end of life in context. Relationships may provide opportunities to help support and comfort; to resolve issues around guilt, love, and forgiveness; or to make the most of what is given in the time remaining. Needs of the dying person are filled within the context of relationships. Relationship problems also can create barriers to the quality of life of the dying patient and the quality of the dying experience by undermining dignity or creating conflict.

Existing research on the interface of social relationships and health outcomes provides a foundation for future research in this area. However, it needs to be extended to adequately address more complex and difficult, yet possibly critical, issues at end of life, such as compassionate love and forgiveness. Identifying the important features of relationships at end of life can help shape quality of care.

Methodologies:

It will be essential for the research plan to address critical issues with conceptual clarity and operational definitions, as well as addressing measurement strategies. There is a wide variety of operational definitions of dying and terminal illness found in research. It will not be sufficient to use phrases such as "a good death" without elaboration and explanation of how this is conceptually understood and how it will be assessed. It will also be necessary to distinguish, conceptually and methodologically, between quality of life and quality of dying. Most research has examined quality of life of terminally ill patients; efforts to conceptualize and assess quality of dying are fewer in number.

It is anticipated that a wide range of research methodologies will be adopted to address these issues. The research plan should include justification for all measures and outcomes. Given that the goal of end of life is palliative rather than curative, it is crucial that the research plan have outcomes that reflect the multiple concerns of interest. Outcomes of quality of life need to extend beyond the purely symptomatic. Research that also includes outcomes for family members and health care providers is desired.

Qualitative research can help define the experience of patients and families through the dying process and help form hypotheses for further study. Purely qualitative work will not be considered, but qualitative research, as a part of a multiple method study will be appropriate.

Applicants may also wish to add religious/spiritual measures or more complex assessments of values and relationships to ongoing studies in various end-of-life settings.

The humanities also contribute to our understanding of end of life and the dying process. Proposals are encouraged that incorporate the humanities with multiple scientific disciplines.

Research on end of life is sensitive and involves a particularly vulnerable population. While the responsibility for ethical research rests with the Institutional Review Board of the institutions submitting applications, the review of a proposal will consider

whether attention has been paid to guidelines and safeguards to take into account the sensitivity of the research. Efforts should be made to minimize distress of study participants.

Examples of Research Questions:

- What are the effects of compassionate love for the dying person? How can compassionate love be encouraged in end-of-life settings and among patients, providers, and families?
- Using conceptually sound and measurable concepts, can we assess the effects of forgiving and being forgiven on the quality of life at the end of life, as well as the bereavement processes?
- What are the effects of the different domains of religiousness/spirituality on quality of life, quality of dying, and symptoms such as pain, shortness of breath, and cognitive disturbances?
- A recognized principle of end-of-life care is to be respectful of the patient's and family's wishes. How can a patient's values best be incorporated in the dying process and end-of-life care? Can we develop ways to more appropriately identify implicit values and priorities of patients and their families?
- What are the effects of hospice and palliative care models that address values, meaning, and spiritual needs on quality of life/quality of dying and coping with symptoms? What might be learned from how these models are integrated into the hospice experience, both in the U.S. and overseas? How can this information be used in other settings (e.g., home, hospital, nursing homes) to improve end-of-life care?
- How do the particular cultural values of a dying person, his or her family, and loved ones, affect the dying experience? What implications are there in the interface between those values and more commonly held values around care provision?
- What is the role of values, human relationships, and religiousness/spirituality in critical care medicine? How might these be addressed?
- How does the inclusion of religiousness/spirituality in the dying process affect the bereavement process?
- What role do religious communities play in providing the kinds of support that patients and families need?
- How might inclusion of spiritual/religious variables in discussions inform decision making around treatment preferences by family and patient?
- Some care providers bring particularly impressive qualities of other-centered love to the care of the dying. What can be learned from the experience of such care providers?
- Are there interventions that effectively incorporate the patient's values and spiritual needs in end-of-life settings? What is their effect on quality of life, quality of dying, and relationships between patients, providers, and family? What is currently being done in end-of-life treatment to incorporate such interventions and resources?
- Are there specific spiritual interventions (music, art, prayer, meditation, sacred rituals, religious/spiritual group support) that effectively address quality of life and meet patients' needs at end of life? Should these focus in depth on specific religious groups, or take a more general perspective? How could these interventions be practically implemented in health care or home contexts?
- Are there interventions to assist health care providers to become more aware of the potential importance of spirituality and relationships at end of life and during the dying process? How do such interventions impact care and the quality of the dying process?
- Are there interventions that can improve positive contributions of other-centered love to quality of life at the end of life?
- Can interventions be developed that enhance the capacity to forgive and feel forgiven at the end of life? Can this contribute to improved quality of life/quality of dying for patients and those in close relationships with the patient?
- The work of the World Health Organization on quality-of-life measures may be useful for end-of-life settings to measure spirituality and quality of life. What can use of these measures contribute to our understanding of quality of life at end of life in an international context?
- Does spiritual growth happen during the dying process? What key features of spirituality are most important to measure in dying patients? How is change in spiritual growth measured close to the end of life?

Proposal Procedures:

Letter of Intent: Due to the Fetzer Institute on or before January 10, 2003

All applicants must submit an original and two copies. Not to exceed two pages. **No facsimiles or electronic submissions.**

The letter of intent must include:

- research aims;
- a brief description of the methodology;
- significance and potential impact of the work;
- phone, fax, e-mail, and address for PI; and
- copy of the curriculum vitae of the Principal Investigator only.

The letter of intent may include a list of suggested reviewers the applicant believes are qualified to review proposals.

Please mail all letters of intent to:

Fetzer Institute
EOL Proposal
9292 West KL Ave.
Kalamazoo, MI 49009-9398

A notification of receipt of the letter of intent will be e-mailed to applicants by **February 15, 2003,** after review, with a follow-up letter to the institution of the principal investigator. The notification will invite a full application submission or reject the proposal. The Institute will not provide feedback beyond the notification response.

Invited Application: Due to the Fetzer Institute on or before May 1, 2003

Those invited to submit a full application will be asked to prepare the following.

Please submit 7 unbound copies of the application. **Only typewritten materials will be reviewed. No facsimiles or electronic entries will be accepted.**

COVER PAGE:
Title of project
Name of P.I., degrees
Department of P.I.
Mailing address
Telephone, fax, and e-mail address

Dates proposed
Total (amount of support requested)

Approval date of institutional review board (IRB) or pending date if this is the case. Note: **IRB application must be submitted to IRB authority when proposal is submitted.** Please provide verification with proposal. IRB approval must be submitted to the Fetzer Institute within 90 days of submission.

Tax-Exempt Status Letter: Please include documentation of your organization's tax-exempt status.

Name of applicant organization
Address

Name, title, address, telephone number, fax number, e-mail address of administrative official to be notified if award is made and address if different from address of applicant organization. Name and title of official signing for applicant organization and address if different from address of applicant organization.

TABLE OF CONTENTS PAGE: please denote on which page(s) the following bold-face items can be found.

Abstract: must contain a clear statement of purpose, explain significance and potential impact of the work, and briefly describe the methodology to be used.

Budget: Direct costs only. Please detail costs and justification for budget items including personnel (role on project, length of appointment, percentage of effort on project, total salary including fringe), consultant costs, supplies, travel, subject reimbursement, other. Applicants may request funds for personnel and supplies only. Funds for travel may only be requested to facilitate collaboration of investigators. No equipment is to be purchased from these funds. The Fetzer Institute does not support indirect costs.

Biographies: Biographical sketches of principal investigator, key professional personnel, and collaborators. Please include relevant publications and experience. Not to exceed 2 pages each.

Statement of Interdisciplinary Collaboration: Interdisciplinary collaboration is encouraged, especially that linking the humanities, such as philosophy, ethics, and theology, with medical and social sciences.

Other support: What other funding are you receiving that might also support this work (e.g., grants, institutional support)?

Statement of Organizational Resources: the contribution of organizational resources available to perform the work proposed.

Research Plan: Include sufficient concrete information to facilitate evaluation. The following information should be included: overall goal and specific aims; background; description of research design and procedures; description of how research results will inform practice and/or policy. This portion not to exceed 3,500 words.

Appendices: applicants may include appendices with relevant information necessary for the proposal. Please assist reviewers and the Institute staff by not overburdening the proposal.

All applications must arrive at the Fetzer Institute on or before May 1, 2003.

Please send applications to:
Fetzer Institute
EOL Proposal
9292 West KL Avenue
Kalamazoo, MI 49009-9398

Questions?
E-mail rfp@fetzer.org
or call 269-375-2000, ext. 269. E-mail inquiries are encouraged. Please check www.fetzer.org for updates.

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